

Keywords: Long-term care, Consumer-Centered Care

## The Consumer/Provider Relationship as Care Quality Mediator

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Support for this research provided by the Robert Wood Johnson Foundation, Building Health Systems Initiative grant # 23246.

## **Background/Significance**

Over the past 10-15 years, concern has been increasing over the quality of the nation's long-term care. Consumer advocacy groups and government bodies, in particular, continue to identify significant failures in the provision of adequate, let alone high, quality, care. There are numerous reports documenting seriously substandard care in both institutional and community-based settings (Harrington, 2001; Health Care Financing Administration, 2000, 2001). In Wisconsin, a Partnership including the State, the University of Wisconsin School of Nursing and the private sector was established to address the quality of home care for frail, chronically ill, low income, adults and younger physically disabled adults. This partnership was designed as a research demonstration program to implement and study a new approach to long-term care.

While the Wisconsin Partnership Program (WPP) was committed to a model of care that revolved around and supported an involved role of the consumers, the absence of an adequate definition or working model of consumer-centered care, particularly so for community-based settings made this difficult. Without such a model, there was little guidance in *how* to provide or measure consumer-centered care programs or services. In addition to a lack of guidance with regard to the "hows" of consumer-centered care provision, a review of literature on consumer centered care also located little discussion on whether and how consumers can be effectively included in the development and evaluation of consumer-centered services or programs (Lutz & Bowers, 2000).

A central goal of the WPP (as well as providers), therefore, was to conduct research on consumer perspectives, to learn how consumers thought about quality. A research team was established prior to implementing the WPP to begin development of guidelines for consumer centered long-term care.

This paper summarizes findings from the series of studies conducted prior to implementing the Partnership Program as well as ongoing data collection within the WPP over a 5-year period, from 1994 - 1999. The paper has two primary objectives. First, it raises questions about how to capture the voices of consumers across long-term care settings, and identifies some barriers to eliciting this information from frail elders. Second, it will provide several examples of what long-term care consumers had to say about long-term care services they were receiving, in particular the mediating role the consumer/provider relationship has on evaluations of quality care from the perspective of frail, older adults.

## **Methods**

**Method:** A grounded Dimensional Analysis was used as the research method (Bowers & Caron, 2000; Janzen, 2001; Schatzman, 1991; Schatzman & Strauss, 1973; Strauss, 1987). This method is based on a constructivist framework and facilitates an examination of the subjects' understandings of a phenomenon (older adults' views of care quality in this instance). It proceeds from a very open to a more focused interview process that allows the researcher to delineate the logic reflected in subjects' descriptions of the phenomenon (care quality). Interviews become more focused as the study evolves. The method also facilitates a comparative analysis of how different groups of subjects (such as consumers vs. providers or across subgroups of consumers and providers) understand care quality, including differences and similarities in the way each views the topic. This method is particularly well suited for research in relatively unexplored areas.

**Subjects:** The subjects represented in this report include: 75 older adults who had received formal services at home, 64 older adults who had received services in a clinic setting, 44 older adults receiving services in nursing homes at the time of the interviews, 46 nurse aides and personal care

workers, 48 nurses, 15 social workers and 5 physicians. Consumers/subjects were drawn from the eligible pool of low income, frail, chronically ill older adults who were able to be interviewed and who consented to an interview.

Data Collection: Early interviews with consumers were conducted using an open-ended, unstructured format. This allowed subjects to determine the direction of the interviews. Later interviews were more focused, designed to build on analysis completed on previous interview data. Consumers were encouraged to explain and illustrate how they distinguished high quality care from lesser quality care, the criteria used to make such distinctions, and to illustrate what they looked for and valued in service providers. Interviews were conducted individually with older adults in a place where privacy was assured. Researchers often met with subjects several times, for very short periods of time due to subject fatigue and illness. The researchers believed it was important to include any subjects willing to participate, despite the challenges of illness and disability. All interviews were audio taped and transcribed for the purpose of analysis. Required human subjects protocols were filed and approved before any data collection occurred.

The settings for data collection included: 7 nursing homes, 3 home health organizations, 2 day centers and 3 Partnership sites. Findings specific to interviews with nursing home residents are reported elsewhere (Bowers, 2002). Providers (nurse aides, nurses and social workers) were also interviewed using unstructured interview formats during the early stages of data collection. Later interviews with providers were more focused, using both early provider interviews and consumer interviews to facilitate comparisons among the two groups perspectives on care quality. It is important to note that data from interviews with providers of long-term care services will be used in a limited way in this paper. Specifically, these perspectives will only be included in a discussion

of "factors" that may stand in the way of discovering what consumers think and how they evaluate the care they are receiving.

Data Analysis: Data were analyzed using dimensional analysis (Bowers & Caron, 2000; Schatzman, 1991; A. L. Strauss, 1987). The method is consistent with a symbolic interactionist perspective (Shalin, 1986), and was later elaborated on by Schatzman (1991). Dimensional analysis involves a line-by-line method of open coding. Coding focuses on how informants/subjects think about the phenomenon (e.g., how they define quality of care). Thus, in this study, consistencies and variations in how subjects understood care quality were 'discovered' through careful analysis of their accounts of care they had received or watched others receiving. Dimensional analysis is a particularly useful method to explore in areas where there is little known, and/or areas in which there are important perspectives missing from our general understanding.

## **Findings**

### *What Stops Providers from Asking*

Operating on the assumption that consumer input is a necessary component of consumer-centered care, providers' views on asking for consumer input are important. While many of the providers participating in the study were supportive of learning about consumer perspectives and preferences, and willing to take consumer perspectives into consideration when planning and evaluating care, many expressed doubts or confusion about the usefulness of asking for direct consumer input concerning wishes and preferences. In particular, some providers reported concern about 1) what choices to ask consumers about, 2) whether asking consumers would yield new and/or useful information, and 3) the objectivity or accuracy of

information from consumers. This was particularly true of the nurses and physicians. In interviews, these providers often described asking consumers about their preferences in care delivery approaches, and receiving responses from consumers that suggested, to providers, that consumers did not understand and/or did not desire to be involved in the decision-making about their care.

In particular, these providers expressed confusion over which choices they could or should ask consumers about, since much of what these providers did required a high level of technical understanding. In general, social service staff could more easily identify areas where consumer input and consumer choice could be integrated into care plans.

Another view expressed by some providers reflected their assumption that asking consumers about their care would probably not yield much new information since this was based on the belief that staff were already knowledgeable about how consumers felt and what their preferences were. Most staff assumed that the contact they had had with consumers, although there were wide variations in the nature and extent of such contact, was sufficient for them *to speak on behalf of the consumers* in most situations.

Finally, several providers expressed a belief that consumer preference would be much too subjective and that their views would be based on faulty assumptions about good care. The belief that consumers are unable to distinguish good care from poor quality care was pervasive. Providers believe that consumers would be unduly influenced by aspects of care delivery that are unrelated to care quality such as the length of wait time, and the provider's personality.

It is worth noting here that some staff in State oversight agencies also expressed concern that including consumers in care planning in general, and asking for consumers' preference or giving them choices, would result in an unsustainable escalation of program costs. As one high-level staff member expressed, "Everyone will ask for a Cadillac." In short, there was considerable skepticism about whether concerted efforts to expand the role of consumers would be useful or productive in planning, implementing or evaluating the quality of care being provided. Consumer centered care was not viewed as something that directly involved the consumer.

Importantly, when asked *how* consumer satisfaction was assessed, several staff described efforts to gain input from individual consumers by asking questions such as: "Are you treated well here?" "Is the care here good?" "How is the quality of your care?" or "Are you getting what you need?"

While not all invitations for consumer input were framed in this way, asking for explicit judgments from the consumer was a common strategy used by providers interviewed. This last point is particularly significant in that the researchers' experience interviewing frail, older consumers during the last 2 decades has revealed that the least effective strategy for ascertaining the consumers' view is to invite these consumers to judge the care. Consumers are generally reluctant to make negative statements. Negative statements about care were generally framed very carefully to avoid explicitly judgmental statements and usually elicited only following considerable interaction, developing trust with the interviewer, and being reassured that there would be no consequences for the provider. This often followed 15-20 minutes of more neutral conversation.

## **Relationship and Care Quality**

### *Consumer "Evaluations " of Care*

Interviews with consumers across groups and settings provided some important insights about consumers' views on care quality and strategies for ascertaining consumer feedback. In many instances, consumers' initial responses to questions about their care were statements such as: "They're all so wonderful." "They are so nice." "He/she works so hard." "I think he/she really likes me." Even consumers who had been identified as 'complainers' generally began discussions about their care experience with statements like this. While not systematically investigated, the research team observed that consumers in the most vulnerable situations, and with the most disabling conditions, often seemed the most positive in their initial statements about their experiences. This vulnerable group appeared least likely to make negative judgements and made the greatest effort to qualify any assessments of their care that were not clearly positive.

### *Complaining*

Most consumers had never used any formal complaint or guidance system. Although they seemed vaguely aware that such a system was available, most would never consider using it. Instead, those who were willing to risk "complaining" often did so by "mentioning" something to a worker they were comfortable with. This was not generally framed as a complaint, just a brief description of something that had happened. Those consumers were certain that such "mentioning" would be clearly understood as a complaint, would be passed on to the appropriate person and would be corrected. Formal processes were avoided since they required the consumer to explicitly "complain" to someone they did not know well and did not trust. It would also require them to reframe the information in a way that was much more judgmental.



### *Distinguishing Good Care from Poor Quality Care*

Many of the consumers' descriptions of care they had received included instances in which the outcomes were less than the consumer had hoped for. For example, in some descriptions of care it was clear to the consumers that mistakes had been made, or that the care they had received was less than ideal. Whether such care was assessed as good or bad depended largely on the relationship between the consumer and provider. Surprisingly, even in those instances where there were serious negative consequences for the consumers, they were rarely willing to assess the care as "bad." Rather, consumers describing these situations often expressed sympathy or empathy for the provider involved. Statements such as "It wasn't her fault" "Everyone makes mistakes." "It couldn't be helped." "These things happen sometimes." were quite common. This was most common in situations where the consumer had a previous positive relationship with the provider in question. One woman described undergoing a procedure that should not have been painful, but was:

"The doctor stood by and the nurse was very, very helpful through the whole thing. She kinda talked me through it `cause it hurt so bad and was really, really good to me. And they were there too when I had to have my leg up with that sandbag on for eight hours at a time and it wasn't their fault that the thing started bleeding again . . . but they were very, very kind to me, both the nurses and the doctors. So I'd say that was one time that I had really good care." (CONS09A)

This has important implications for consumers' ability to participate in care evaluations. Many examples such as this can be found in consumer descriptions of care that had led to negative outcomes. When asked about such instances, the explanations consumers gave were often more likely to focus on the *intent of the provider than on the provider's competence or the outcome*. For example, in one situation where a consumer experienced a serious negative, preventable outcome, she prefaced the description with "Maybe that wasn't supposed to

happen, but I know she means well. She really tried." In fact, in many such instances, providers were forgiven and care was assessed as high quality based on the consumers' perceptions of the providers intent:

"And I told that to the doctor, and she was so sympathetic about it, that I couldn't believe my ears, that she was telling me such kind things and she was so sympathetic that it was just unreal And then when she left she had me come into her office to talk to her, and the tears came to my eyes and I just cried and I told her she's the best doctor in the world."

"...I mean, they did the best they could. And they were concerned. They had that... an attitude that was concerned, you know, that made me feel better to know that they were taking good care of me."

"I can't remember what he said but what he said made you think he was concerned about how I felt. It was the touch and the attitude that he was doing the best he could."

Conversely, in situations where the consumer did not have either a previous or positive relationship with the provider in question, assessments were more likely to reflect on the competence or good will of the provider.

In those instances where consumers were upset about negative outcomes, they often attributed those outcomes to a lack of concern or attention from the provider rather than to technical inability.

Another example of this is illustrated by a consumer in a nursing home who commented on not being ambulated for several days in a row. This consumer had just finished explaining how the walk down the hall was the highlight of her day, and important to her recovery. "Well, I don't always get my walk, but it's OK!. I guess I don't really need it. Maybe other people need it more than I do. I guess it doesn't really matter so much if I get it."

Consumers consistently expressed the belief that care quality was largely related to provider intent (as described earlier) rather than provider technical competence or knowledge. This belief seemed to be based on an assumption that differences in provider performance were generated from differences in provider caring. That is, providers who 'cared enough' to make sure care was provided in an effective manner would thus provide higher quality care. Consumers gave many examples of how a caring attitude led to care processes (and higher quality) that substantially differed from care given by an unfamiliar or uncaring provider.

The relationship between health care provider and consumer has often been talked about by both parties as largely irrelevant to the quality of the care provided, as 'just' part of the amenities. Findings from this study reveal that relationship is much more relevant to care quality than is suggested by these discussions. Consumer assessments of care quality were often embedded in consumers' beliefs about the nature of the relationship they had with the provider.

### *Relationship as Mediator*

Consumers consistently described how the familiarity resulting from an ongoing relationship with a care provider led to higher quality care. They provided many examples of how such familiarity (biographical or medicobiographical expertise) on the part of the provider was necessary to provide high quality care. For example, one older woman described the consequence of her doctor understanding her dread of being hospitalized: "He would never ask me to do that. He knows how nervous it would make me." This particular woman had cats at home that she was very attached to. When she was gone for any length of time she worried incessantly about their wellbeing. Because her doctor was aware of this, he would only hospitalize her when there was absolutely no other option. Knowing this, she was willing to

go into the hospital only when he advised it. If another doctor wanted to admit her to a hospital, she would refuse to go since her dread of leaving her cats had not factored into the decision. This left her uncertain about the necessity of hospitalization.

### *Making the Self Visible*

An older, retired chemistry professor described the high quality of care he received from one doctor who always talked with him about the chemistry involved in the drugs he prescribed for the professor. The professor was much more compliant with the prescriptions of that particular physician than he was with others, citing the importance of knowing about the chemistry. The retired professor also talked with pride about this physician who "treats me like an intelligent human being, and not just an old man." Thus, the ability of a provider to bring some continuity of the self, to make the person inside the failing body visible, resulted not only in a higher quality relationship for patients but higher quality care, including in some cases, greater compliance with treatments.

An important component of the long-term relationships with providers mentioned by many of the consumers interviewed was that when providers had adequate knowledge about the patient's personal and medical histories, mistakes were likely to be minimized. Several consumers recounted stories of how this operated in clinical situations. For example, consumers talked about how frightening it was when a health care provider asked questions about their medical histories for important health information. Asking such questions was perceived by these consumers as the provider relying on the consumers' memory to make important decisions. Most consumers found this frightening. For example, one woman recounting her visit to a clinic commented. "He didn't have my records with him or hadn't read

them. He said, 'Now tell me what drugs you are taking and what you are taking them for?' Well, I knew I was in trouble."

Another important component of expertise generated from long-term relationships between consumers and providers, is the ability of familiar providers to integrate their knowledge of individual fears and intolerances into a plan of care. For example, one woman described in an interview her intolerance of nausea. She would not take a medication that left her nauseous, not even slightly. Her provider was aware of this and, without any intervention or reminders from her, always addressed the likelihood of nausea occurring with a new medication or treatment. Knowing of her intolerance, her physician might use 'the second best drug' in order to preclude the possibility of that particular side effect. In addition, when nausea was a possibility and he still wanted to use the drug, he discussed with the consumer just what they would do if she had any nausea.

What makes this example significant is that many of the older adults interviewed for this study had stopped taking medications that gave them unpleasant side effects. In many of these cases they had not informed the physician that they had done this. In fact, in several of these situations, the consumer continued to tell the physician that he/she was still taking the drug. These older adults, in many cases, were unwilling to inform physicians about untoward drug effects or that they were not taking a drug. Some feared this would make the physician angry. Some feared they would get the physician in trouble. Some believed this was evidence that the physician did not know how the drug worked or what it did. These later responses were more likely if 1) there was not a long-standing relationship or 2) the physician had not informed the patient that the side effects were possible.

### *Consumer Evidence for Care Quality*

Analysis of the consumer interviews also gave insight into the types of evidence consumers use to assess the quality of care they are receiving. That evidence closely parallels the consumer descriptions of quality described above. For example, consumers identified the importance of evidence that their provider has remembered personal details about them. There was quite a range in both the type of details and the degree to which they reflected a level of intimacy or familiarity. One older woman, Edith, explained how upsetting it had been when a physician she knew well had referred to her as Ethel. She was suddenly faced with the realization that she did not have the relationship with this provider that she had believed to exist. In addition, her concern that 'He might be giving me Ethel's medicine' shifted her view of the quality of care that she was currently receiving and would likely receive in the future. In another instance, an older man described how his physician was working with a medical student and had told the student about the man's wife, what his adult children were doing, and how complicated his medical situation was. The details were all recounted accurately. This gave the older man tremendous reassurance that his physician would also remember other details that were important to his care.

Some consumers also described how explicitly integrating personal details into care and treatment plans served as evidence of care quality. For example, a woman who was hospitalized explained how her physician made the decision to keep her overnight because of her transportation difficulties. Another described how the doctor's actions during clinic visits reflected his understanding of the patient's history: "I know you always get cold, so I'll put a heater in Room 2. You'll have to wait a bit longer, but the room will be warm." Another described how her physician asked how she would follow her diet while she took care of her young grandchildren, even asking what assistance might be required. In each of these cases,

the consumers described in detail how important this was as evidence for caring and competence, and how much easier it was to follow treatment plans under these conditions. In contrast to these examples, several consumers talked about how upset and anxious they became when providers forgot important details like this, dismissed them as unimportant, or did not integrate these into a plan of care. In both situations, consumers were reluctant to remind providers, and generally did not do so. Many of these latter situations led to consumers simply ignoring the advice and treatment plans they had been given.

Making and/or maintaining eye contact was also widely cited by consumers as evidence of care quality, suggesting a provider was more caring, more attentive and more likely to remember and integrate important biographical and medicobiographical information. In addition to a lack of confidence about the care they would receive, lack of eye contact resulted in consumers revealing less relevant information to a provider.

Finally, several consumers identified a process some providers engaged in that was extremely important evidence of *both* a good relationship and a high level of care quality. This process can be described as "clearing the way" for good quality care, or increasing the likelihood that the care provided by others in settings other than the doctor's office (hospital staff, specialists, etc) would be enhanced. For example, a severely disabled man described how his primary care physician met him on a hospital unit to explain to the nurses how he should be transferred to avoid injury. In several other instances, consumers spoke about special details of their care (the rapidity of blood sugar changes, the great significance of a seemingly benign symptom) and the lengths providers would go with others to distinguish how *this* consumer's care was unique and different from usual. This consumer perspective expanded the scope of expertise of the provider, and insured high quality

care from other staff that did not have an intimate relationship with the consumer. This latter type of evidence was particularly important for consumers who had very serious illnesses that could worsen quickly or who had very unusual symptoms.

## **Discussion**

Much of what was learned from this research is consistent with other research on patient satisfaction. This study adds to that research by probing in more depth how older adults think about quality, and how they collect evidence and make determinations about the quality of their care. Most importantly, however, this study adds to our understanding about the nature of the relationship between consumers and health care providers and how these relationships affect the quality of care patients receive and the willingness of consumers to follow a recommended treatment plan.



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